Indigenous Data Sovereignty

Indigenous Peoples have always been "data warriors".[1] Our ancient traditions recorded and protected information and knowledge through art, carving, song, chants and other practices. Deliberate efforts to expunge these knowledge systems were part and parcel of colonisation, along with state-imposed practices of counting and classifying Indigenous populations. As a result, Indigenous Peoples often encounter severe data deficits when trying to access high-quality, culturally-relevant data to pursue their goals but an abundance of data that reflects and serves government interests regarding Indigenous Peoples and their lands.

The concept of Indigenous Data Sovereignty is a relatively recent one, with the first major publication on the topic only appearing in 2016.[2] Indigenous Data Sovereignty is defined as the right of Indigenous Peoples to own, control, access and possess data that derive from them, and which pertain to their members, knowledge systems, customs or territories.[3, 4, 5] Indigenous Data Sovereignty is supported by Indigenous Peoples' inherent rights of self-determination and governance over their peoples, territories and resources as affirmed in the United Nations Declaration on the Rights of Indigenous Peoples (UNDRIP), as well as in domestic treaties. Indigenous Data Sovereignty recognises that data is a strategic resource and provides a framework for the ethical use of data to advance collective Indigenous well-being and self-determination.[6, 7]

In practice, Indigenous Data Sovereignty means that Indigenous Peoples need to be the decision-makers around how data about them are used. Given that most Indigenous data is not in the possession of Indigenous Peoples, Indigenous data governance is seen as a key lever for addressing Indigenous

Data Sovereignty. Indigenous data governance harnesses Indigenous Peoples' values, rights and interests to guide decision-making about how their data are collected, accessed, stored and used.[8] Enacting Indigenous data governance results in Indigenous control of Indigenous data through both internal Indigenous community data governance policies and practices and external stewardship of Indigenous data via mechanisms and frameworks that reflect Indigenous values. The COVID-19 pandemic has highlighted the necessity of enhancing Indigenous data governance as well as the pressing need for increased data for governance and decision-making.[9]

Growth of the Indigenous Data Sovereignty Movement

The Indigenous Data Sovereignty movement grew substantially in 2020 due to continued socialization of the concept; enhancement of Indigenous Nation, community-based data efforts; and the COVID-19 pandemic. The Global Indigenous Data Alliance, or GIDA,[10] is an international network of networks, organizations and individuals pursuing Indigenous control of Indigenous data, engaged policymakers, data communities and scholars. GIDA members advanced recommendations for COVID-related data;[11] compiled an edited collection exploring Indigenous Peoples' data and the link with, implications of and space for change within the data/policy nexus;[12] and guided initial operationalization of the CARE Principles.[13, 14, 15]

COVID-19, Indigenous Peoples and data

COVID-19 has deepened existing inequalities. In many countries, the impacts on Indigenous Peoples have been particularly severe, through higher infection and fatality rates, as well as economic losses, social upheaval and discrimination.[16] The adage "data is king" has found fertile

ground during the pandemic, with governments and researchers leaning heavily on data to monitor and manage the impacts of the pandemic and direct their responses. For Indigenous Peoples, COVID-19 has amplified the importance of data sovereignty, raising new challenges and opportunities.

There are numerous well-rehearsed arguments for why Indigenous Peoples have rights to timely, accurate and relevant pandemic-related data.[17, 18, 19] Without high-quality disaggregated data, it is impossible to know the extent of the pandemic's impacts on Indigenous Peoples, or to deploy well-informed responses. There is growing research on how worldwide data deficits are compromising Indigenous Peoples' health and wellbeing during the pandemic. Key challenges include: a failure to collect Indigenous identifiers; misclassification; limited data disaggregation; lack of data sharing and use agreements; and data analyses that are implicitly or explicitly racist, and which lack context or knowledge of Indigenous communities.[20, 21, 22] These issues exist, to some extent, across all nation states. However the size of the problem – and its impacts – vary enormously. Indigenous Peoples in low- and middle-income countries generally have the least access to data and information, fewer resources to protect their communities, and experience an increased risk of persecution.[23, 24]

The collection and use of Indigenous data is not without risk. The pandemic has provided many examples of why strong forms of Indigenous data governance are needed to address concerns around data harm, group privacy, consent, racist surveillance and algorithmic profiling.[25, 26, 27] In a digitally-connected world, the power of governments and corporations to define, identify and track "problem" populations is historically unprecedented. In some cases, governments have used the pandemic to gain access to Indigenous data in ways that, in "normal" times, would be inconceivable. In the US, for example, tribal nations had to furnish sensitive information on their tribal expenses, citizens and bank account numbers to the Department of the Treasury in order to access funds through the *Coronavirus Aid, Relief and Economic Security (CARES) Act*. In a massive data breach, these data were subsequently downloaded by unknown government officials and emailed to non-government employees.[28]

Indigenous Data Sovereignty researchers and activists have been quick to call out pandemic-related data injustices,[29, 30, 31] and to offer up possible solutions and alternatives. An international collaboration of Indigenous Data Sovereignty researchers developed Indigenous data guidelines for COVID-19 related data, setting out the minimum requirements for Indigenous-designed data approaches and standards, inclusive of Indigenous rights to data governance and decision-making.[32] The guidelines, adopted by the Research Data Alliance, outline obligations for funders, governments, researchers and data stewards in the collection, ownership, application, sharing and dissemination of Indigenous data, specifically in relation to COVID-19 related issues. Indigenous Data Sovereignty networks have also made compelling arguments on the need for targeted investment in Indigenous community-controlled data infrastructure that prioritizes Indigenous needs, supports communality capacity and resilience, and improves the flow of information for effective public health response.[33] It is hoped that in the short-term, Indigenous control over Indigenous data will help advance access to needed resources in the pandemic. In the longer term, Indigenous Data Sovereignty is seen as a mechanism for the system change that is so desperately needed.

Indigenous Data Sovereignty and policy

Data are a cultural, strategic and economic resource. As deployed by nation states, data about Indigenous Peoples form the primary evidence base on which Indigenous policy is framed. Yet, Indigenous Peoples, globally, remain largely alienated from the collection, use and application of data about them, their lands and cultures.[34] Consequently, most existing Indigenous data, and the policy shaped by those data, neither recognise Indigenous knowledge and worldviews nor meet Indigenous Peoples' data needs. Relatedly, Indigenous Peoples encounter distinctive obstacles to fully realising the power of data for driving effective policy. Indigenous policy, therefore, needs to be operationalized as a dual concept, referring to the linked understandings of policy developed and implemented: by a nation state in relation to its Indigenous Peoples

and by Indigenous nations in relation to their own peoples.

In 2020, key Indigenous Data Sovereignty scholars from around the globe came together to produce an edited collection, *Indigenous Data Sovereignty and Policy*, to address this data/policy conundrum.[35] The impetus for the book was to elucidate, from Indigenous perspectives, the problems and challenges of the Indigenous data/Indigenous policy connection. As scholars, we sought to address these issues across socio-cultural spheres, across Indigenous nations, and across nation states. Arguments for the problematics and remediating strategies of data/policy interactions were framed within the central concept of Indigenous Data Sovereignty.

Representing a global endeavour by the networked Indigenous Data Sovereignty scholars and activists, this book sought to highlight how, in the Indigenous realm, the connection between data and policy is imbued with both potential harms and benefits. For example, the continuing power imbalance between those who determine policy and those who are subject to it frequently means that the value of data-driven policy does not accrue to Indigenous Peoples whose interests they purport to serve. As shown by Indigenous scholars from Australia, Sweden, Mexico and Colombia, the resultant policy framework is rarely benign, embedding existing inequalities rather than redressing them.

Other contributions such as that on Indigenous-led health and data initiatives in Canada, the role of data in the contested narratives of victimhood in the Basque Country, the clash of values on data that draw on Indigenous knowledge, and the legacy of colonialism and epistemic injustice, have all highlighted the centrality of power dynamics and often bitter contestation occurring within the data/policy space, cross-nationally. The scholarly writings, however, have also provided multiple examples of the value and validity of Indigenous Data Sovereignty in supporting the transformative potential of data. These have included the contributions to Māori aspirations for self-determination, the practical implementation of Indigenous Data Sovereignty for Pueblo Peoples, the role of the Te Mana Raraunga Māori Data Sovereignty Network in establishing Māori data sovereignty as a legitimate policy discourse, the active work of embedding Quechan Indigenous Data Sovereignty practices, and Kaupapa Māori epidemiology grounded in

Māori values, knowledge systems and ontologies. In these examples, data provide the policy evidence for the benefit of those to whom it relates – Indigenous Peoples.

The collected scholarship demonstrates that the pace of the Indigenous data revolution varies significantly by nation state. In all countries, however, disrupting the existing Indigenous data and policy paradigm remains a continuing task. A shift will require more than formal data agencies taking a different approach. Rather, change requires a re-ordering of data infrastructure alongside prioritizing, mostly for the first time, the data interests of Indigenous Peoples. Above all, if lasting change is to be achieved, changes must be systemic and involve power sharing with Indigenous communities and nations.

Operationalizing the CARE Principles

Released in September 2019, the CARE Principles for Indigenous Data Governance (Collective benefit, Authority to control, Responsibility, Ethics) set minimum expectations for guiding the inclusion of Indigenous Peoples in data governance across other governments', institutions', corporations' and organizations' data ecosystems.[36, 37, 38] In 2020, GIDA engaged through research projects, webinars and collaborations to socialize global data and policy communities to the CARE Principles. Through a series of webinars with ORCID,[39] continued collaborations with the Research Data Alliance and its International Indigenous Data Sovereignty Interest Group,[40] and numerous other virtual engagements, the CARE Principles reached a broad audience across North America, Australia-Asia, and the globe. Translations of the CARE Principles from English to Spanish and Vietnamese increased access to GIDA for Indigenous Peoples and others in the Americas and Asia.[41]

The CARE Principles seek to shift data relationships from regulated consultation to value-based dialogue that forefronts Indigenous cultures and knowledge systems within data ecosystems. The CARE Principles complement the FAIR Principles[42] (Findable, Accessible, Interoperable, Reusable), and making data both CARE and FAIR creates space to infuse provenance, protocol and permissions across the data

lifecycle in order to promote equitable outcomes and benefits from data access, use, reuse and attribution. Operationalizing the CARE and FAIR Principles for Indigenous Peoples' data requires tools to guide the inclusion of Indigenous knowledge within data systems.

Tribal and other institutional laws, policies and practices as well as digital infrastructure can reflect and enact the Indigenous Data Sovereignty and the CARE Principles. Some of these mechanisms existed prior to the Indigenous Data Sovereignty movement and the release of the CARE Principles, such as: Indigenous nations' own codes, guidelines, research review processes, and technical infrastructure and human resources; support for Indigenous Data Sovereignty within the reports by the United Nations Special Rapporteur on the Right to Privacy in the Digital Age;[43] and infrastructure tools that enrich metadata such as the Traditional Knowledge Labels.[44]

In 2020, a proliferation of policies and guidelines that support the CARE Principles and Indigenous Data Sovereignty were developed, including the Australian Institute of Aboriginal and Torres Strait islander Studies (AIATSIS) Code of Ethics for Aboriginal and Torres Strait Islander Research,[45] the draft United Nations Educational, Scientific and Cultural Organization (UNESCO) Recommendation on Open Science,[46] the Policy Partnership on Science, Technology, and Innovation (PPSTI) Statement on Open Science,[47] and "Data sharing respecting Indigenous Data Sovereignty" in the Research Data Alliance COVID-19 Working Group Recommendations and guidelines on data sharing.[48] Digital infrastructure tools were also expanded, such as the development of Biocultural Labels[49] and the Institute of Electrical and Electronics Engineers' (IEEE) efforts to create a Recommended Practice for Provenance of Indigenous Peoples' Data.[50] However, more mechanisms are needed, as well as criteria to assess and evaluate how non-tribal institutions are enacting the CARE Principles.

To reinforce the operationalization of CARE, GIDA and collaborator initiatives have identified a need for and co-production of: (1) CARE Criteria for implementation, such as a set of indicators for the principles; (2) training and educational offerings on various elements related to Indigenous data, sovereignty, and governance for Indigenous Peoples as rightsholders and others as stakeholders; (3) alternative licensing and

agreement systems that support communities in their engagement with external data systems; and (4) mechanisms for provenance, permission, and protocols that embed attribution and use parameters defined by Indigenous Peoples throughout the data lifecycle.

Opportunities and challenges ahead

While strides towards advancing Indigenous Data Sovereignty and the CARE Principles increased in 2020, challenges around Big Data, Open Science and Open Data remain.[51, 52, 53, 54] Additional concerns at the close of 2020 included the implementation gap that occurs when institutions support Indigenous Data Sovereignty but do not enact it despite adopting policies and guidelines; how to operationalize Indigenous Data Sovereignty and the CARE Principles within the private sector – where arguably the biggest risks lie; and broader outreach and collaboration with Indigenous Peoples worldwide, particularly in Africa, Asia and Latin America.

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